Consent to Participate in the Alzheimer Prevention Trials Webstudy

Below is a consent form to participate in the **Alzheimer Prevention Trials (APT) Webstudy**. If you click the checkbox below, it means you are agreeing to participate in this research project.

Please read the information presented below carefully before giving your consent. First, we will describe the Webstudy itself and then provide a description of what it will mean for you to consent to become a participant in the APT Webstudy. Participating in the APT Webstudy is voluntary.

To print a copy of this consent form, please click the print icon at the top of this document.

What is the APT Webstudy?

The APT webstudy is being conducted by Dr. Paul Aisen of the Alzheimer's Therapeutic Research Institute (ATRI) of the University of Southern California, Dr. Reisa Sperling of Harvard Medical School and Dr. Jeffrey Cummings of the Cleveland Clinic Lou Ruvo Center for Brain Health, in collaboration with the National Institutes of Health (NIH).

The APT Webstudy is for older adults who are interested in participating in clinical research studies in Alzheimer's.

What is the purpose of the APT Webstudy?

The goal of the APT Webstudy is to use web-based assessments to develop a large, standing, online cohort of individuals who will allow their cognitive status to be tracked over time. From this cohort, we will identify individuals who may be good candidates for new clinical trials at research sites in your area. While anyone who is over 18 can join the APT Webstudy, these clinical trials are targeting older adults who may be at an increased risk for developing Alzheimer's disease (AD) or who may already be showing signs of memory problems.

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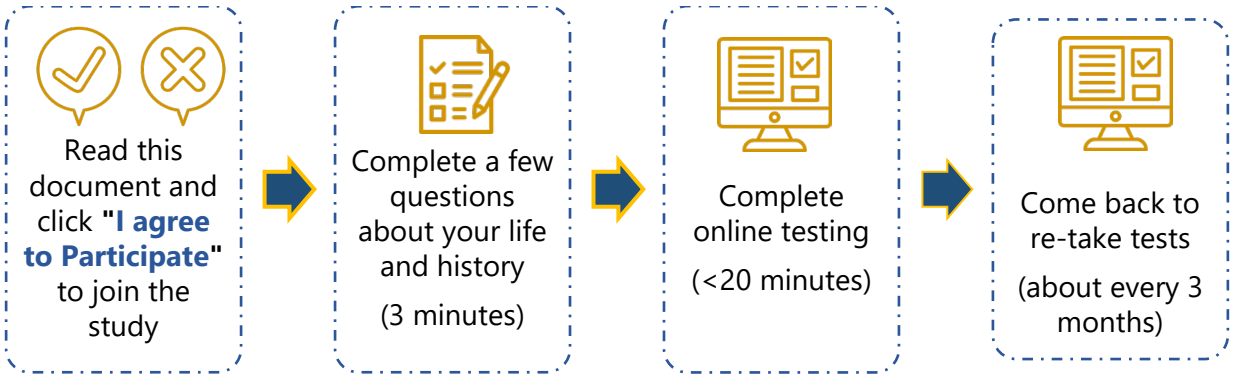
How many people will take part in this Webstudy?

We are seeking at least 200,000 people over the age of 18 to join the APT Webstudy.

What happens if I join APT Webstudy?


Read this document and click "I agree to Participate" to join the study
Complete a few questions about your life and history
(3 minutes)
Complete online testing
(<20 minutes)
Come back to re-take tests
(about every 3 months)

If you decide you want to join the APT Webstudy, you will first read this consent form and click "I agree to Participate".

After agreeing to participate, you will complete some brief questions about your life and medical history. These should take about 3 minutes to complete.

Next, you will be asked to complete computerized (online) tests. These can be completed on any device connected to the internet (for example: a smart phone, or other internet-connected device like your computer, laptop, or tablet).

- The exact tests that you will be asked to take may change over time. For example, you may be invited to complete questionnaires about how you feel about your memory, or you may be asked to take computerized memory tests.
- Some of the tests will be quick and should take about 5 minutes to complete, others may take a little longer (less than 15 minutes) and will be completed over a few days.
- Completing these memory tests, or answering questions is always optional. You can skip any tests or questions that you don't want to complete.

This will be you first "visit" as a part of the APT Webstudy! There is no cost to join, and no payment to you for joining.

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What happens after I join the Webstudy?

You will be invited to return to the APT Webstudy to re-take these online tests and may be invited to complete new questionnaires over time. Some of the tests and questionnaires you will re-take every 3 months, others will be about every 6 months. But don't worry, you will receive reminder messages from the APT Webstudy letting you know when it's time to come back to re-take a test, asking you to update your profile, or inviting you to take a new test!

ATRI researchers will be looking at the data generated from the Webstudy and will track your progress. When you return to the Webstudy and re-take the online tests, you will be able to see how you are performing over time.

The information we learn from you, both from your performance on the memory tests and the information you provide about yourself, will be used to help us identify if you may be a good candidate for a clinical trial.

If we think you may be a good fit for a clinical trial, and if you agreed, your contact information will be shared with a partnering research clinic in your area. You may be invited to visit that research clinic for an in-person visit to complete additional tests. You will be asked to complete a separate consent form at the research clinic before any procedures are done. You do not have to agree to visit the research clinic to remain in the APT Webstudy.

If a partnering clinic site is not available near you, we may be able to provide you with information on other clinics in your area that you may wish to consider contacting for an in-person visit, or other resources that may be available to you.

How will data about me be used?

Study data collected from you will be used in different ways:

- To learn about changes in your cognitive status over time, to provide you with opportunities for in-person visits at partnering sites, and to let you know about opportunities to participate in clinical trial research. To do this, data collected about you may be shared with researchers who partner with the APT webstudy.
- To help inform the scientific research community by broadly sharing de-identified research data (data that cannot be used to identify you). Data sharing is important for further translation of research results into knowledge, products, and procedures

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to improve human health. Before any data is shared with the research community, all links with your identity will be removed, so it will not be possible to tell who you are from the data that is shared.

- Additionally, de-identified data may be used and shared in social media, in addition to scientific presentations and publications in scientific journals.

What if I no longer want to be part of the APT Webstudy?

Participating in the APT Webstudy is voluntary. You may withdraw your consent to participate at any time. To withdraw, log in to www.aptwebstudy.org, go to your Study Profile page, and choose "Revoke Consent". You may also email us at info@aptwebstudy.org to let us know you would like to withdraw your consent. After withdrawing, you will no longer receive emails from the APT Webstudy. The data you have already provided will not be removed or deleted. This is important for the scientific integrity of the Webstudy.

What are the risks of joining the Webstudy?

Your information will be kept private and will be stored in secure servers, but there is always a risk of loss of privacy. **Click here** to read our Privacy Statement. You will be notified in the event of a breach of confidentiality.

The questionnaires from the APT Webstudy may be upsetting or distressing to you and may make you feel bored or uncomfortable. You are free to decline to answer any questions you do not wish to.

Participation in the APT Webstudy involves completing some research assessments through commercial providers and the research procedures require involvement via an internet connection. Due to this, there may be increased confidentiality risks associated with study participation. However, no personally identifiable information will be provided to our commercial providers and we take all reasonable steps to ensure the information you provide to the APT Webstudy is kept safe and secure.

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What are the benefits of joining the Webstudy?

There is no guarantee that you will personally benefit from joining the APT Webstudy. By joining, you will be given the scores of your tests, and you will be able to see changes to your scores over time. It is possible that by joining the APT Webstudy, you will be informed about opportunities to participate in clinical trials which may be of benefit to you.

Who can answer my questions?

For questions about the APT Webstudy, please email us at info@aptwebstudy.org, or call us at (858) 877-3135.

For questions and additional information about giving consent or your rights as a member of the APT Webstudy, please call the USC Institutional Review Board (IRB) Office at 323-442-0114 between the hours of 8:00 AM and 4:00 PM, Monday to Friday (or email at hrpp@usc.edu). The USC IRB is the IRB of record for the APT Webstudy. The IRB is a research review board that reviews and monitors research studies to protect the rights and welfare of research participants.

If you wish to participate, please click on the button below that says **'I Agree to Participate'** and follow the instructions.

If you do not wish to participate, please click on the button below that says **'I Do Not Agree to Participate'** and no additional information will be collected.

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